

Lay Summary

250,000 of the UK population have IBD. It is not known how many of these are gay or lesbian (GL) but we can estimate the figure to be about 14,000 people. The nature of IBD is very likely to be the same in GL people, but we do not know if the psycho-social and illness-related concerns are similar, or whether there are additional or different issues associated with being gay with IBD. Gay men and women have historically been stigmatized (labelled as unacceptable) by their sexual identity, but have usually developed personal management strategies for dealing with this and have learnt how to interact positively with an historically often hostile social world. It is not known if these skills help or hinder in managing a chronic (and potentially stigmatising) illness such as IBD. Even today, society and public services can treat GL people badly, so that they avoid seeking healthcare. This reluctance to seek help may have additional consequences for GL people who also have IBD. This group may face additional difficulties because of their alternative identity and because of having IBD. Even a specialist IBD support group such as Crohn's & Colitis UK may not be accessed by GL people if they fear socially negative or hostile responses or if it is believed that the organisation is unlikely to address the specific issues associated with being gay with IBD. The proposed study aims:

1. To understand the issues and concerns related to IBD amongst the GL population, and demonstrate whether these are similar or different to the concerns of the non-gay IBD community
2. To explore social and psychological aspects of IBD in gay people, and how these are managed.
3. To explore the parallels between coming out about sexual identity, and coming out about IBD.
4. To provide information which will enable NACC to understand the needs of this specific group and to identify what NACC can therefore do to support and increase its GL membership.

We aim to recruit GL people with IBD to the study using a wide range of GL networks (social and activist groups, health advisory websites, gay radio and publications). Anyone can take part, as long as they identify as gay or lesbian, have Ulcerative or Indeterminate Colitis or Crohn's Disease, are over 18 years old and live anywhere in the UK. We will collect information from them in two ways: **Phase 1:** we will use paper and online questionnaires to collect information about lesbian and gay identity, how people feel about their IBD, quality of life, disease activity and IBD-related issues of concern, and demographic data (age, male / female, for example). This will help us to show whether concerns are similar to those of the non-gay IBD community, and then follow up self-identified issues faced by gay people with IBD in the second stage.

Phase 2: we will carry out in-depth face to face interviews with about 15 people from Phase 1 (to include men and women, UC and Crohn's disease, out as gay or not) to gather detailed data about IBD-related psychosocial issues.

We will look at the information in different ways, using statistical methods to analyse questionnaire data, and looking for themes and stories in the interview data. The proposed benefits of the study include:

1. Helping NACC to be more inclusive towards members with different identities and lifestyles;
2. Provide data which helps NACC to understand the needs of their gay members, and to identify ways of attracting and supporting this specific group.
3. Providing evidence to help NHS staff improve their care of people with IBD who are gay.
4. Further understanding of issues relating to coming out about illness can support telephone, on-line and personal counselling, and help in the production and design of specific information and self-help materials for all people with IBD.

We will share our findings through NACC News, academic publications, conference presentations, news articles via our gay community recruitment sites, and with all participants.